

Statement for the Record by Irma Rappaport, CT: House Select Subcommittee Hearing 9/21/22

Prior to March 2020, when all visitors were restricted from having access inside long term facilities, I might have offered different suggestions for improvements in long term quality care. But now that I and thousands of Essential Caregivers across the United States have watched our loved ones decline and die because we could not assist them, my first priority is to make sure this never happens again. Unfortunately, in many states lockdowns are still occurring, even for reasons other than COVID. The pre-pandemic problem of staff shortages became even worse. There was no oversight inside these facilities without family members and ombudsman allowed inside. State surveys were suspended. Family members could not help “fill in the gaps” when there was not enough staff to provide adequate care to residents.

I was not my mother’s visitor. For over 10 years, I was her unpaid personal aide. I did direct care (toileting, dressing, washing, feeding, brushing teeth, cutting nails, wound care, exercising, taking her outside, and taking her to doctors) 3-6 times a day, 7 days a week. On March 9, 2020, I was told I was not allowed in. I hoped it would be for a short time once testing and PPE were available, but it turned out to be for 11 months. I watched and advocated from my mom’s window several times a day, 7 days a week and took notes and photos on what I saw. I shouted through the closed window or called the facility because her food and drinks were not close enough for her to reach, food was missing from her tray, she wasn’t wearing her glasses or slippers, she was put into her wheelchair slumped instead of sitting up straight, she was sitting in the dark in the late afternoon in fall and winter because the lights in her room weren’t put on, or the shades were down so that I couldn’t see in. These were just some of the things that I saw. Sometimes I saw staff with their masks down below their noses and I told them to pull up their masks when they were in my mother’s room. But I couldn’t see what was happening in the rest of the building. The trauma of watching from the closed window still gives me nightmares. Sometimes staff was hostile to me for asking them to help with things I saw. They were short-handed and overworked.

In September 2020, new CMS guidelines allowed family to come in for Compassionate Care Visits, for reasons other than “end of life.” My mother had lost over 15 pounds by then, but I still was not allowed in. I kept watching from the window and, on days when she struggled to feed herself, staff came in for a short time and then left, instead of staying with her the whole time to help and encourage her. On more than one occasion, I caught them taking away her tray after 20 minutes, with most of the food still on the tray, when it usually took her 45-60 minutes to eat.

On a nice fall day that year, I came to the window and saw her sitting alone in the room, begging to go outside and pointing to the window. I called the facility and asked if they could bring her outside so I could sit with her. They said “hold on” and then came back to the phone and told me, “Sorry, we’re too busy.” On another occasion, dinner was brought into her room when she was loudly asking to go to the bathroom. I asked them from the window to help her, but they said it was dinnertime and they couldn’t help her until after dinner. I would have helped her and then given her dinner. When I got my COVID vaccines, my arm hurt for a day each time. I feel badly that I couldn’t comfort her when she got her vaccines.

The worst thing that happened during my mother’s isolation from me was that she was moved to a different room in the building during the pandemic. The facility seemed to be moving residents around during that time. In February 2021, on a cold snowy day, I was called by the facility and told that my mother was unresponsive. When I entered her room, it was so hot in there that I had to open the windows. She was in bed, with her lips bleeding at both corners. Her blood tests showed that she was critically dehydrated. She passed away a couple days later. I was told by a CNA, when I was inside, that it was “the hottest room in the building.”

Long term care lockdowns are still occurring across the states to this day, despite the availability of vaccines, PPE, and testing, for reasons such as a single case of COVID or a case of scabies. Statistics have shown no uptick in cases of COVID and the other variants when family were allowed back in.

Since May 2022, I have been finding constituents across the United States to attend virtual meetings with me and the health legislative assistants of U.S. Representatives, to ask their representative to cosponsor HR 3733-The Essential Caregivers Act. All of our 5 House Representatives in Connecticut have cosponsored the bill and now I am helping other states. There were 32 cosponsors in May and now there are 74 Republican and Democratic cosponsors, including the co-leaders of the bill, Representative John Larson of Connecticut and Representative Claudia Tenney of New York. There is no mention of Essential Caregivers in President Biden's Nursing Home Reforms, but this bill will allow up to two resident-designated Essential Caregivers access to a federally funded facility for 12 hours a day, while being required to adhere to the same written safety protocols as staff. Improving the quality of nursing home care, such as staffing shortages, is not a simple or quick fix, but passing the bipartisan HR 3733-Essential Caregivers Act will ensure that no resident in long term care will ever be totally isolated again.